

**Testimony**  
**Of**  
**Rita Bergmann**

**U.S. House of Representatives**  
**Committee on Commerce**  
**Subcommittee on Telecommunications, Trade, and Consumer Protection**  
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Thank you Chairman Tauzin and Members of the subcommittee for inviting me to tell my story today.

My name is Rita Bergmann and I'm a 13 year old, seventh grader at Rocky Hill Middle School in Clarksburg, Maryland. I've lived in the same house on a hilltop with my mother, father and brother since I was born, and have always enjoyed family activities. My greatest interests are and have always been ballet, creative writing, and hiking. I also love traveling to beautiful areas in America, and doing all sorts of activities outside and relating to nature.

I am a straight A student with all around interests in many areas. I participate in many extra-curricular activities, including the student government, drama club, math team, and environmental club. I also am a peer mediator, and a member in groups to prevent smoking in people of all ages. Until December of 1994, I also played basketball, baseball, ran track, and did a large amount of ballet. I was "on toe" at age 10, and within a month of dancing "on toe" I was dancing three days a week with people who had 3 years of experience "on toe". It is rare for people to start toe before the age of 12. Ballet meant the world to me. I had taken ballet classes since I was 3 years old.

My life was very average for most kids my age, as far as medical issues went, up until December 1994. Ten days before Christmas that year, I went to the doctor for a third appointment complaining of pain in my leg. I danced, and I knew leg pain, and this was bad. For the first two doctor visits it was assumed that because I was so athletic, I must have an injury or strain from ballet. But this time they took X-Rays and drew blood. No injury here. I had osteosarcoma, a form of bone cancer.

As I tell you this story, I am calm and together, but as it all happened, my composure was a mess. I never knew what to make of it all. I had so many mixed emotions... asking "Why me?" as I tried to pull what was good from the whole experience.

The cancer was located directly above my knee on the femur (my thigh). I also had two spots of something on my lungs--whether cancer, or just a noncancerous abnormality was not known at that time.

After a biopsy and an operation to install a broviac central line which would administer the chemotherapy, I was pulled quickly into the worst nightmare of my life. Extremely sick and weak after suffering many side-effects from the chemo -- fainting, losing a lot of weight -- I was put on intravenous feeding through my broviac (12 hours a day, lasting from late January until August that year). This supplied my body with the much needed nutrients chemo was robbing me of, and which I was also too sick to receive from food. Out of school and all activities, I couldn't turn my head in fear of vomiting all that was left inside of me up, not that I had the energy to move anyway.

On April 19th, 1995 I had my first operation to save my leg. My entire left knee and half of my femur was replaced with a polyethylene and titanium knee joint and rod, and all tissue and muscle adjacent to the tumor were removed. I stayed that next week in intensive care, then in the oncology unit of Children's National Medical Center in Washington, D.C. Naturally, the only thing I remember from that week was pain.

Five days later, the dressing was removed. Unfortunately, the wound did not heal as expected. All of the skin and muscle had died, and the following day I found myself back in the operating room having a muscle flap and skin grafts done. This was, as one of my doctors put it, "the end of the envelope procedure." We weren't sure at this point if my leg would be saved.

Finally, after three months, I was able to once again put weight on my leg. A big milestone.

One fun thing did happen for me that summer when I got to go to Camp Friendship, a camp for kids with cancer, in Olney, Maryland. Here, I really started the process of starting to walk again while I mixed with kids who understood my situation and had

been there too. Unfortunately, the spots on my lungs, which hopefully would have disappeared with chemo, remained, and so in mid-August, I had a lung operation. Thank God those spots turned out not to be cancerous.

When the school year started again in September, 1995 I was ready to leave this medical life I was leading behind. I went to school as often as my chemo schedule permitted. I got back to my same old after-school activities, time with friends, and homework while I battled the cancer.

I remained in a wheel chair until January, 1996 when the chemo finally finished and the broviac was removed. As soon as the effects from chemo began to wear away, I was back up doing all of the activities I loved, minus ballet.

Between January 1996 and today, I did as much as my surgeon, Dr. Malawer of the Cancer Institute, will let me do, and a bit more. I always have to be careful not to jump, run, or do any activities which might cause a fall and harm my prosthesis.

In the summer of 1996 I went camping with my family near Acadia National Park in Maine for a week. We are, and always have been a very nature oriented bunch. I challenged myself to hike all the trails I used to, and more. Not a single cliff face we hiked before cancer went unclimbed.

I'm competitive and set high goals. Accomplishing them meant a lot to me. I came back with pictures of me doing cartwheels in the sand, and sitting on cliff edges we had just climbed up. I couldn't have made it to any of these hide-outs if I had had an amputation.

That summer we also went backpacking in a remote mountain valley in West Virginia, also a trail I did before. I carried a 15 pound pack for a 7 mile round trip hike. On that trip, we climbed up a mountain by our campsite on the second day of our trip -- no day for resting sore legs, I was busy climbing.

Though the chemo and it's side effects are over for the most part now, my leg is a never ending concern. At any moment I could take a serious fall and have to have another joint replacement, and regardless of that, in about 10 years, I will have to have another replacement.

Polyethylene makes these joint replacements possible. Amputation is the only other option for many patients.

I've seen and can imagine an artificial leg and it is not the arrangement I want. I want to be able to always walk on my own leg, bend my knee, wiggle and point my toes. I don't want to take off a titanium leg each time I go to sleep, and I want to be able to hold on to the ballet I miss so passionately with the few steps and spins I can do.

I like this way, of having my own leg; and I know many who feel the same way.

I can't imagine how such a needed material could just cease to be made available. Such a rash act would change so many peoples' lives, cause pain and unneeded suffering, and smother many dreams. I hope light can be shed on these aspects of polyethylene's uses so people like me will have the chance to keep their own leg.

If polyethylene wasn't available to make a prosthesis, the only choice for my leg would have been amputation; but this way I can go on and reach for some of my greatest dreams -- to continue climbing mountains and to really dance ballet again.

Thank you for your time and attention.